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Testimony in strong opposition to HB 5898 An Act Concerning Aid in Dying for Terminally III Patients Public Health Committee March 18, 2019

On behalf of Not Dead Yet and Second Thoughts Massachusetts

www.notdeadyet.org

Co-Chairs Abrams and Steinberg, Members of the Committee:

I am the New England Regional Director for Not Dead Yet, the national disability rights group that has long opposed the legalization of assisted suicide. I am also the director of Second Thoughts Massachusetts, sister organization to Second Thoughts Connecticut. We are disabled people united against legislation and cultural messages that it's better to be dead than disabled. I urge you to reject assisted suicide bill HB 5898. Too many people will lose their lives through misdiagnosis, insurance company profiteering, social pressure, and untreated depression.

The bill promises individual choice and autonomy, but delivers neither.

Many people diagnosed as terminally ill are not dying. As everyone knows, doctors make mistakes all the time. At least 12-15% of terminal diagnoses are wrong, and thousands of people "graduate" yearly from their six month hospice benefit. If assisted suicide is legalized, non-dying people stand to lose months, years, or decades of meaningful life. Actress Valerie Harper provides one example: she was given three months to live in 2013, yet lives on more than five years later. There are certainly people, now dead, who would today be walking around, grateful that their terminal diagnosis was incorrect.

Patient choice isn't possible as long as access to treatment is controlled by, in the words of Congresswoman Alexandria Ocasio-Cortez, the "for-profit death panels" of the health insurance industry. Legalized assisted suicide instantly becomes the cheapest treatment, and crowds out long-standing treatment options. People have already been denied treatment but offered assisted suicide. The Oregon Health Authority clarified last year that people can become "terminal" by having treatment denied by an insurance company, by not being able to afford treatment, and by stopping treatment that extends life.

Abuse of older adults is rampant, and it is estimated that one in 10 people over the age of 60 is abused every year, almost always by adult children and caregivers. The state's role in assisted suicide ends with the prescription, and given that no independent witness is required at the death, we have no way to know whether someone took the poison willingly or not, knowingly or not. The fact that the bill immunizes everyone involved forecloses the possibility of an investigation.

Like other assisted suicide bills, HB 5898 reimagines depression as a rational response to serious illness. But depression does impair judgment, that's one of its main features. Absolute hopelessness and

seeing no way out are common feelings in severe depression. Depression can lead people to see suicide as the best response to their problems. But depression is treatable, death by suicide isn't.

What ever else assisted suicide is, it is not about pain. Pain is a medical problem that palliative care can control. As renowned palliative care expert Dr. Ira Byock has testified,

If I thought lethal prescriptions were necessary to alleviate suffering, I would support them. In 34 years of practice, I have never abandoned a patient to die in uncontrolled pain and have never needed to hasten a patient's death. Alleviating suffering is different from eliminating the sufferer. Allowing a person to die gently is importantly different from actively ending the person's life.

To better understand why people participate in the program, simply take a look at the just-released 2018 Death with Dignity report. It shows, once again, that it's not physical pain that pushes people towards assisted suicide, but "existential distress" over the disabling aspects of their serious illness.

Doctors report people's "end-of-life concerns" revolve around negative reactions to dependence on others, loss of abilities to do valued activities, loss of social respect ("loss of dignity"), feeling like a burden on others, and shame around uncontrollable body functions like incontinence. Pain, even when combined with fear of pain, is only the sixth listed concern.

These suicidal feelings emerge out of prejudice against people with disabilities. Whether it's support for a disabled teenager Jerika Bolen's planned suicide or yet another disability snuff film ("Me Before You," "Million Dollar Baby," etc.), there is a constant drumbeat of "better dead than disabled" influencing and reflected in assisted suicide laws.

Those "end-of-life concerns" suggest a meaning of dignity that is fragile and easily lost through disability and dependence on others. The people acting on these views, proponents admit, tend to be wealthier, better educated, and people with a strong preference for control. This is presented as a good thing.

Assisted suicide participants are also overwhelmingly white. 97% of program suicides in Oregon have been non-Hispanic white, in a state 22% nonwhite. In Colorado and California, 94% and 89%, respectively, of program participants were also non-Hispanic white. In the 3 states, with 25 years of data, only one person identified as black has used the program.

We have a public health problem, but it isn't certain people's lack of dignity, it's the turn to suicide as a social solution by a powerful social class. High rates of white suicide are an unaddressed social problem. Just as white suicide in general is much higher than rates for people of color, so whites use assisted suicide almost exclusively.

We disabled people have lives that frequently look like the lives of people requesting assisted suicide, but we reject as bizarre the notion that personal dignity is somehow lost through physical dependence on others, or because we are not continent every hour of every day. We already encounter massive prejudice in the medical care system, which is all too ready to have us die without treatment. I know people with disabilities living vibrant, active lives contributing to the community who have been encouraged to sign Do Not Resuscitate orders or decline life-saving treatment.

Let's make sure that people have the choice and support to live comfortably at home before offering hastened death. In your deliberations, please think about Connecticut residents, elders and disabled people who may be vulnerable and without the sort of support and control assisted suicide proponents take for granted, innocent people who will be impacted by this piece of bad social policy. Invidious quality-of-life judgments have no place in social policy.

Please reject this bill and the discrimination it promotes. Thank you.